

Going digital: opportunities and barriers in the use of technology for health research

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Abstract

Digital health refers to the use of novel information communication technologies in healthcare. The use of these technologies could positively impact public health and health outcomes of populations by generating timely data, and facilitating the process of data collection, analysis, and knowledge translation. Using selected case studies, we aim to describe the opportunities and barriers in the use of technology applied to health-related research. We focus on three areas: strategies to generate new data using novel data collection methods, strategies to use and analyze existing data, and using digital health for health-related interventions. Exemplars from seven countries are provided to illustrate activity across

Resumen

La salud digital se refiere al uso de tecnologías de información y comunicación para el cuidado de la salud. El uso de estas tecnologías puede tener un impacto positivo en la salud pública y en la salud de la población mediante la generación oportuna de datos, facilitando el proceso de recolección y análisis de información y la transferencia del conocimiento. El objetivo es describir las oportunidades y barreras para el uso de tecnologías aplicadas a la investigación en salud utilizando como ejemplos estudios de los autores. El estudio se enfocó en tres áreas: estrategias para generar nuevos datos usando métodos de recolección novedosos, estrategias para usar y analizar los datos existentes e intervenciones en salud basadas

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these areas. Although the use of health-related technologies is increasing, challenges remain to support their adoption and scale-up—especially for under-served populations. Research using digital health approaches should take a user-centered design, actively working with the population of interest to maximize their uptake and effectiveness.

Keywords: digital health; health technology; artificial intelligence; data collection; web-based intervention

en tecnología. Se presentaron ejemplos de siete países para ilustrar actividades relacionadas con las áreas mencionadas. A pesar de que el uso de tecnologías en salud se está incrementando, existen dificultades en su adopción e implementación a gran escala, especialmente en poblaciones vulnerables. Las investigaciones en salud digital deberían adoptar un diseño centrado en la persona, trabajando activamente con las poblaciones de interés para maximizar su aceptación y efectividad.

Palabras clave: salud digital; tecnología en salud; inteligencia artificial; recolección de datos; intervención basada en web

‘Digital health,’ an umbrella term for the use of a wide variety of information communication technologies in healthcare, has a great potential to contribute to the improvement of public health and health outcomes for individuals.¹ Digital technologies can enable innovative approaches to the needs of patients, professionals, and health managers. This potential is greater when technologies are developed under human-centered paradigms that consider the specificities of human-technology interactions and are comprehensively integrated into health systems.²

Access to large volumes of data is now enabled by a multitude of sources including internet sensors, wearables, and smartphones, which enable fast, real-time data capture. The use of data science and artificial intelligence (AI) has made it easier to deal with the large volume of structured and unstructured data collected from traditional and novel collection methods. Both interdisciplinary fields were designed to learn from the data and to translate these findings into usable knowledge and have grown in prominence in health research in recent years.³

This paper describes the opportunities, barriers, and challenges brought about by the use of digital technologies in health-related research to generate new data, utilize and analyze existing data, and deliver interventions using novel approaches. Working examples of digital health are presented throughout the manuscript; these examples were selected based on previous experiences by the authors.

Technology in health-related research: opportunities and barriers

Opportunities of using web-based data collection methods

Health-related research historically relied on traditional data collection methods, *i.e.*, face-to-face, mail, and phone interviews, to investigate the health of the population. These methods generally require both interviewers and participants to be present at the same time

and place.⁴ Although this remains the dominant mode of data collection, it is time-consuming and logistically complex, and generates substantial costs associated with human resources, transportation, as well as printing and posting costs.⁵ Phone interviews can lower these costs and logistics; however, they are often difficult to conduct in settings where landline infrastructure has decayed or where mobile plans are constantly changed.^{6,7}

Web-based data collection can, in some cases, simplify and overcome these barriers. Web-based surveys can be easily set up by researchers on their own, or via a third party, using existing web servers to support questionnaire design and data storage and analysis. Logistics related to the recruitment of individuals for research can be simplified if email and social media are used to invite participants.⁷ If the study targets a well-defined population, invitations can be made using direct messages, while an open snowball recruitment strategy can also be conducted with public posts on social media if the aim is to reach the largest possible number of participants. Given most social media platforms are freely available and already familiar to users, the material and transactional costs associated with their use are minimal compared to traditional methods.⁸ The use of self-reported questionnaires also contributes to the reduced personnel and operational costs, since salaries and charges related to transportation of interviewers will be substantially less.⁴ Another advantage of web-based research is that their acceptability could be higher compared to other methods when investigating sensitive subjects, *e.g.*, drug use, domestic violence, sex-related, since they rely on self-reported questionnaires or can be approached by using alternative methodological designs given the sensitivity of the subject matter.^{4,9,10} Finally, web-based research makes the process of data collection and analysis faster. Once the link to the questionnaire is made available, participants can start responding to the questionnaire and their responses are automatically saved in a structured format. Also, if questionnaires are designed featuring branching logic and item validation, the time spent on data consistency

checks is reduced –narrowing the time gaps between collection, analysis and reporting.⁴

Barriers faced when using novel data collection methods

Collecting health-related data using digital platforms is still incipient in many parts of the world, and consequently, their widespread use involves some challenges. Most web-based studies are still conducted in countries with high internet penetration using reliable, high-speed broadband or mobile infrastructure. Such infrastructure is highly variable in many low- and middle-income countries, particularly in rural and remote areas which also experience high levels of inequalities in health care access.¹¹ Compounded with the limitations in infrastructure, the socioeconomic adversities related to education and literacy, particularly digital literacy, and experience with self-administered tools may also hamper the reach to disadvantaged groups.¹²

Another important limitation of web-based studies is that response rates can be difficult to quantify, as the denominator is often unknown, and typically are lower compared to studies using traditional data collection methods.¹³ The potential for non-response bias could therefore be greater, which could compromise the external validity of the data collected. Web-based samples may include participants who are younger, wealthier, and more highly educated than those participating in paper-based research.¹⁴ Participation and follow-up in web-based studies vary depending on the method used to contact participants; however, they can be boosted by providing incentives after participation or by sending reminders using different means of contact.^{13,15-17}

Another barrier that needs to be considered in low resource settings is the lack of access to appropriate, easy-to-use, open-source software to conduct web-based research. Although this barrier is decreasing as more software products and services become available, researchers should be aware of potential data security, privacy, and governance issues associated with software policies. If a third-party service were to be used, all sensitive information could be accessible to the company that runs this service, and it might not be governed by the same ethical standards in data protection and sharing as is health research. In addition, depending on the location of these servers, state or even country laws might be contravened.¹⁸

Cases of technology use in health-related research

Building on our collective experiences in digital health research in diverse country contexts, we discuss different uses of technology in the research environment, focusing on three areas: generating new data, using and analyzing existing data, and delivering digital health interventions.

I. Data generation

coortesnaweb, longitudinal web-based research in Pelotas, Brazil

The *coortesnaweb* is a gamified web-based platform developed to conduct epidemiological research in the context of the 1993 Pelotas birth cohort.¹⁹ The original birth cohort comprises 5 249 participants who were born during 1993 in the urban area of Pelotas, a Southern Brazilian city. In 2015, all members of the birth cohort were invited to attend a research clinic as part of the 22-years of age follow-up, and 3 810 members of the cohort were interviewed face-to-face.¹⁹ Out of these, 3 537 (93%) responded to the interview without the help of a third individual and had Internet access, thus being eligible for the *coortesnaweb* study.

During 2018, eligible individuals were invited to register into the platform through e-mails and direct messages using WhatsApp and Facebook.⁷ Once registered, participants were approached with three questionnaires exploring anthropometric measures, alcohol consumption, and physical activity. Five additional questionnaires were made available in the *coortesnaweb* platform inquiring about internet use, crime and violence, lactose and gluten consumption, sleep quality, and smoking over a five-month period. Gamification strategies were introduced into the platform to encourage participation and reduce dropouts. After responding to each questionnaire, participants earned virtual points and badges that could be used to unlock other features in the platform, including access to personal results about their health (*e.g.*, level of physical activity, nutritional status) and comparing their results to pooled estimates from other participants.

A total of 1 307 individuals (1 307/3 537, *i.e.* 37% of all eligible) registered on the platform; the response rates for the eight questionnaires ranged from 31.2% (408/1 307) to 69.4% (908/1 307), the range depending

on the completion rate of the different modules used (15). The overall participation on the web-based survey was lower compared to face-to-face interviews, mainly due to the lack of financial incentives in the online part of the study. Engagement was higher for the first four months of study and was perceived to decrease from the fifth to the eighth month of study. A new wave of data collection will be conducted in 2021/2022, using both self-reported questionnaires and passive data collection using smartphone sensors. Other retention strategies (e.g., financial incentives and gift cards) are being studied to increase participation and to reduce participant dropout.

*Simplified Cardiovascular Management (Simcard)
Study in rural Tibet, China*

Simcard was a 12-month cluster randomized controlled trial conducted between 2012-2014 in 27 rural villages in Tibet, China.²⁰ The study aimed to evaluate the effectiveness of a simplified cardiovascular management program delivered by community health workers with the aid of a smartphone-based electronic decision support system.²⁰ During the monthly follow-ups, the smartphone-based application allowed the community health workers to retrieve a participant's record, and enter their blood pressure, current lifestyle habits, current medication use, previous medical history, new conditions, contraindications, and side effects. All collected information was locally stored on a smartphone device. Information was then processed via an inbuilt algorithm to provide decision support to community health workers. The decision support was based on a "2+2" model, two medication prescriptions (low-dose diuretics and aspirin) and two lifestyle modifications (salt reduction and smoking cessation). At the end of each follow-up, all collected data and decisions were uploaded onto a freely available, open-source central medical record system that is used in many low- and middle-income countries (OpenMRS).²¹

The qualitative evaluation of the trial found that all community health workers considered the smartphone-based decision support system helpful to support the regular patients' follow-ups. The main challenges found were related to unreliable mobile network coverage and to the need for a simpler language in the user interface.²²

*SMARThealth extend study: cardiovascular
disease risk screening and management in Indonesia*

SMARThealth Extend involves the implementation and evaluation of a digital-enabled primary health care intervention in Malang district, East Java, Indo-

nesia.²³ The study involved a cross-sectional baseline survey, followed by delivery of a multifaceted digital health intervention focused on better identification and care for people at high cardiovascular disease risk. A baseline household survey involved screening of all individuals aged 40 years and above in eight villages representing urban, semi-urban and rural areas in Malang District. A team of 25 enumerators were trained to collect and enter information for cardiovascular disease risk assessment into the SMARThealth data collection application installed on a seven-inch tablet device. The application stored information on sociodemographic and economic status, relevant medical history, smoking status, and physical activity. It also allowed the recording of anthropometric measurements, including height and weight. Blood pressure was measured using a bluetooth enabled digital sphygmomanometer that allowed the readings to be wirelessly uploaded to the application. Random blood glucose was measured with portable glucometers and readings were manually entered into the application. At the end of the interview, the inbuilt clinical decision support system of the application identified individuals at high risk of cardiovascular disease, or that had abnormal blood pressure or glucose readings requiring referral to a nearby doctor. Data were stored locally on the tablet device and securely uploaded to a server hosted at the coordinating research institute using OpenMRS.²¹ This allowed the application to function in zones with limited internet coverage and asynchronously update data whenever an internet connection was available.

During household visits, which occurred from January to March 2016, enumerators screened 22 093 individuals using this system, equating to 99% of the target population. Several factors contributed to the high response rate: i) the high acceptability of the enumerator team within the community; ii) the ability to share results with participants in real-time and to refer high-risk patients to a nearby doctor; iii) the logistical facilities for participants to get their blood pressure and glucose levels measured in the vicinity; iv) the user-friendly data collection method using tablets with branching logic and real-time item validation. The main technical limitations included limited battery life on the devices, inability to charge the tablets during long power cuts, glare on the tablet screen when used in an outdoor environment, and frequent Bluetooth unpairing between the tablet and the sphygmomanometer. These challenges were addressed with practical solutions such as providing external power banks, using spike busters, and charging multiple devices with a backup generator, as well as encouraging data collection inside the household.

The WebCovid-19 follow-up of the 2019 Rio Grande birth cohort, Brazil

The WebCovid-19 is a series of web-based follow-ups nested into the 2019 Rio Grande birth cohort.^{24,25} The birth cohort interviewed at baseline almost all mothers who had a baby in the city of Rio Grande, Southern Brazil, reaching 99% coverage (n=2 314). After the Covid-19 outbreak, in 2020, those women who participated in the perinatal study and lived in the urban area of the city were invited to participate in repeated web-based surveys that investigated the impact of the pandemic on their lives (2 051 / 2 314, 87% of the original cohort).

Thus far, two web-based follow-ups have been conducted and, on both follow-ups, information has been gathered on sociodemographic characteristics, lifestyle, general and mental health, fears and worries, domestic violence, and sleep patterns during the pandemic. The Research Electronic Data Capture (Redcap) application was used to develop and manage the survey.^{24,25} In the first and second follow-ups, approximately 50% of women were located and approached, with a refusal rate below 2%.^{24,25} The main challenge to follow-up was outdated contact information for the participants, with few of them using landlines and many with cellphone numbers that have changed, which also meant that contact via WhatsApp was not possible. Facebook was often the most effective strategy for locating the women, rather than reliance on mobile numbers as previously proposed by others.⁷

The ACCISS study experience, Peru

The Addressing the Challenge and Constraints of Insulin Sources and Supply (ACCISS) study aims to improve access to insulin.²⁶ In 2020, a mixed-methods study was conducted to study the impact of measures taken during the Covid-19 pandemic –such as lockdown, social distancing, closure of international borders, and restrictions of movement within the country including cancelation of internal flights– on access to care for type 1 diabetes patients as part of ACCISS activities in Peru.²⁷ The study included web-based surveys and in-depth interviews with patients and caregivers, healthcare providers, and pharmacists who dispense insulin.²⁶ The web-based survey was designed using Redcap, incorporating a patient registry, error checking, and collecting digital signatures for informed consent. Social media such as Facebook fan pages and groups of diabetes associations, WhatsApp groups of patients or health personnel, and Twitter were used to disseminate the survey, with support from type 1 diabetes patients' associations who promoted the survey among their members for over a month. Despite

this, the response rate was lower than desired –of the 1 000 patients with type 1 diabetes reported to belong to a patient association, only 212 answered the survey, of whom 155 were considered eligible according to the inclusion criteria. For the interview component of the study, fewer challenges were encountered. Most interviews were conducted through cellphone calls due to variable internet access. There were a few difficulties in establishing rapport with the interviewees over the phone, perhaps due to their having found previous phone interviews burdensome. Also, selection bias was present in the study, as most participants reported using the private sector, while most of the Peruvian population relies on the public health sector.

2. Use existing data

Understand patterns and behaviors using semantic analysis, Brazil

In Brazil, a group of researchers developed an algorithm using natural language processing and machine learning techniques to investigate patterns and analyze the semantic content of messages.²⁸ The aim was to study user engagement and evaluate if topics discussed by users can presumably reflect motivation, attitudes, and behaviors. The algorithm was applied to posts and comments published between 2011-2014 by 110 000 one-time users of the online social network Reddit who were participating in a web-based weight management intervention. Findings highlighted that specific topics of conversation, *e.g.*, friendship, counting calories, self-esteem, were associated with successful weight loss, $\geq 5\%$ loss from baseline weight.²⁸ This highlights that semantic analysis of topics discussed in online social communities can support the development of behavior change interventions for weight loss. Moreover, most of the topics identified by the semantic analysis are usually not included in weight loss programs (*e.g.*, friendship and self-esteem) and, if included, could have higher impact on behavior change and weight loss.

Linkage of outcome data for the Salt Substitute and Stroke Study, China

The Salt Substitute and Stroke Study is a recently completed five-year, cluster-randomized controlled trial in rural China, which aimed to evaluate the effectiveness of salt substitute on stroke, cardiovascular disease, and mortality.²⁹ Six hundred rural villages across five provinces were randomly allocated to be part of the intervention or control group. Villages assigned to the intervention group received free of charge salt substi-

tutes. In order to be able to determine the effects of the intervention on the outcomes of interest, a data linkage approach was performed between routinely collected data from the study and the New Rural Cooperative Medical Scheme health claims data and mortality surveillance system to identify both non-fatal and fatal outcomes.³⁰ Although linking data to official statistics is a low-cost alternative for outcome identification and evaluation of large-scale randomized controlled trials, the official statistics should have good quality in terms of complete rates and coverage to be considered as a valid alternative. The health claims data used by the Salt Substitute and Stroke Study exhibited a limited validity (approximately 60% sensitivity) and are still under examination.³¹

3. Digital health interventions

Interventions focused on behaviors: Studies from Brazil, Argentina, Guatemala, and Peru

Web-based behavior change programs have the potential to reach many people while being affordable and accessible anywhere and anytime according to personal preferences. Despite the potential large-scale benefits, results have been heterogeneous regarding their effectiveness. A systematic review found clinically small and comparable weight loss and dietary and/or physical activity changes when comparing between web and offline based interventions in overweight and obese adults.³² The results may be different for short-term (<6 months) weight loss interventions, with web-based interventions leading to greater weight loss than offline based ones.³³

In Brazil, a randomized controlled trial comparing the effectiveness of a web-based platform for weight loss for 1 298 people found that personalization was key to improved outcomes.³³ The groups that received personalized feedback generated by a computer or by an online dietitian coaching program resulted in greater weight loss and usually showed more positive changes in dietary and physical activity habits after six months of the intervention. This suggests that web platforms might be a good strategy for tackling overweight and obesity through lifestyle habit changes in the short term. This can be particularly useful in contexts in which the demand for professionals to support people with excess weight cannot be met. Moreover, the personalized intervention delivered by the online coaching also led to high levels of user engagement, which in turn was associated with a higher odds of clinically significant weight loss.

In Argentina, Guatemala and Peru, a randomized controlled trial assessed the effectiveness of a

one-year mHealth intervention, combining monthly motivational interview calls and SMS text messages to promote changes in diet and physical activity among adults from low-income neighborhoods. The study found small but significant reductions in body weight and high-fat and high-sugar foods intake in the intervention group.³⁴ Importantly, an assessment done in the Peruvian participants four years after the last follow-up found that those who received the intervention still had lower body weight and BMI than those in the control group. There was a dose-response association with greater reductions among those participants who received at least 50% of the scheduled calls in the intervention.³⁵ Among the challenges observed were the real-world difficulties to secure appointments; therefore, the delays introduced meant that not all participants were able to receive 'higher doses' of the intervention, which were designed as four-week periods to accommodate the motivational interviews followed by weekly SMS messages. Notably, the recognition of baseline readiness to change may be important to better target groups as needed in future studies.³⁶

Decision support tools for cardiovascular disease management and linkage to electronic medical records and follow-up, Australia

Evidence has shown that electronic decision support systems (EDSS), especially in primary health care settings, can lead to better quality care as well lower health costs.^{37,38} Researchers at The George Institute for Global Health developed its first EDSS platform in 2011. It provides clinical decision support tools for chronic disease management and prevention in primary health care services. In Australia, it was integrated with primary care electronic medical record software systems which are used by over 95% of general practitioners nationally and was designed to help health professionals implement recommendations from clinical guidelines and to make it easier for patients to understand their risks of heart disease and stroke.³⁹ Following this trial in Australia, the concept was adapted for use on mobile devices in resource-constrained primary health care settings. It has since been upgraded to support the detection and ongoing management of other non-communicable diseases and related risk factors and has been adapted for implementation in six countries in the Asia-Pacific region.^{39,40} Despite its potential, there remain challenges to fully integrate the EDSS into the existing health systems. The varying organization, structure and technologies used in these systems may require different approaches to integrate the EDSS.

Technology to prevent diabetes complications, Peru

Diabetes care and diabetes complication prevention need self-management strategies to reduce the burden of health care systems. A systematic review found that thermometry is an effective intervention to prevent the incidence of diabetic foot ulcers.⁴¹ Based on this finding, a randomized controlled trial in Peru implemented the use of thermometry in 172 participants from two public national hospitals and one study arm was supplemented with a mHealth intervention involving SMS and voice messages.⁴² It was found that 90% of the participants who returned their logbooks reported adherence to temperature measurement above 80%. However, the mHealth arm was not effective to reduce the incidence of diabetic foot ulcers.⁴²

This study faced some challenges, including the high proportion of people with diabetes that did not know how to open an SMS message. Trying to overcome this barrier, voice messages were also considered in the study design. However, slightly more than half of the sample (57%) said they preferred voice messages, while the remaining ones stated they preferred SMS mainly due to their flexibility on reading messages at their own convenience. Sending SMS messages was also a challenge, since the automated software used to send intervention messages presented some failures, and, therefore, only 50–75% of all messages were sent to a fifth of the participants. Hence, using mixed methods to deliver digital interventions was very beneficial to minimize some drawbacks specifically related to a particular method.

Challenges and the way ahead

Retaining user engagement in web-based research or interventions is an important aspect of digital health. Engagement, as a concept, refers to the effort expected from the user and can be defined differently according to the studied domain, depending on the desired outcome of the interaction. For instance, engagement with advertisements is expected to end when the user focuses or clicks on the ad, whereas engagement with social media is expected to last longer and remain beyond a particular session, inviting users to return to the website in the following days or weeks. Pragmatic trials have shown that low engagement and adherence are usual in web interventions, and this could impact the effectiveness of the intervention.⁴³ Apart from impacting the effectiveness of interventions, if low participation is associated to aspects related to exposures or outcomes of interest, studies that focus on associations or causal relationships might be hampered by selection bias. Hence, it

is important that the design, logistics, and recruitment process be carefully planned to reduce the probability of selection or non-response bias and to achieve high participation rates.

Another inherent challenge to digital health interventions or web-based research is the digital divide; this refers to inequalities on Internet coverage or access to electronic devices, which are usually lower among the worse-off. Therefore, if the idea is to cover a representative sample of the population, or intervene similarly on all subgroups of the population, it is important that researchers take into consideration the digital divide during the design of digital health research platforms. For instance, oversampling specific groups of the population might be a good strategy to overcome the digital divide and to avoid widening the gaps between the worse- and better-off.

A sense of reward, perceived usability, aesthetic appeal, ability to attract user-focused attention, a sense of novelty, *i.e.*, curiosity and interest in the interactive task, as well as the feeling of being “drawn in” and “having fun” with the digital intervention are recognized as determinants of user engagement.⁴⁴ These determinants can potentially guide intervention development. Co-design with end-users is pointed out as a key factor to incorporate these determinants of user engagement in the development of the intervention. Moreover, tailoring the intervention to individual needs rather than using “one size fits all” approaches seem to be more likely to engage users more effectively.⁴⁵ Also, interventions that require less effort and dedication from the users are more likely to be used for longer periods of time. Examples of interventions requiring less effort by users are those that are commonly used by populations and that incorporate sensors and wearables enabling automatic data collection rather than constant requirements for data input by the user.⁴⁶

Closing remarks

With the increasing Internet coverage and access to connected devices worldwide, using the Internet to support health research is already a reality –as can be seen by the use cases described in this manuscript. Importantly, the exemplars provided are derived from pioneering studies being conducted in the Latin America and Asia-Pacific regions, thus advancing the field of health research relevant for low- and middle-income countries, with substantial contributions to the field of reverse innovation.⁴⁷ Taking advantage of the expanding capillarity of these technologies, both private companies and Internet communities are developing novel tools to collect, store, and process and analyze health-related data. Although

some key distinctive features related to the research environment used between data collection and generation of results are different, the ultimate goal is similar to previous approaches: to translate findings into health interventions and policies to positively impact the health of populations. However, there are still some challenges in adopting technology for health research, especially in low- and middle-income countries and in the more disadvantaged subgroups of the populations. In this review, we have visited opportunities, barriers and examples of digital health research, and we have learned that the effectiveness of web-based surveys and interventions depends on the design and context in which it is inserted, with emphasis on on-the-ground research case studies. Studies using novel approaches should be designed taking into consideration the profile and background of the population of interest to maximize their effectiveness, embracing the opportunities offered by technology whilst being cognizant of the existing barriers that may affect any given endeavor. The lessons provided in this review are primarily related to the field of non-communicable diseases but can well inform other areas that would benefit from processes directly related to digital health.

Declaration of conflict of interests. The authors declare that they have no conflict of interests.

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